

*Next Meeting – Monday, May 5, 2008 – 2 PM  
Appoquinimink State Service Center  
Middletown, Delaware*

**STATE COUNCIL FOR PERSONS WITH DISABILITIES  
BRAIN INJURY COMMITTEE  
April 7, 2008 – 2:00 PM  
Appoquinimink State Service Center  
Middletown, DE**

**PRESENT:** Devon Dorman, Co-Chair; Brian Hartman, Co-Chair; Dr. Jane Crowley, A.I. DuPont Hospital; Laura Cygan, Parent advocate; Janet Leitch, Consumer; Lora Lewis, DPH; Mike Merrill, VR/U.S. DVA; Tom Parvis, DVR; Al Rose, DDC; Liz Schantz, Consumer; Wendy Strauss, GACEC; Kyle Hodges, Staff and Linda Bates, Support Staff

**ABSENT:** Ray Brouillette, Easter Seals; Linda Heller, DSAAPD; Virginia Corrigan, Christiana Care; Aaron Deede, Consumer; Ellen deVrind, Christiana Counseling; Tony Horstman, SCPD; Dr. Dan Keating, Bancroft Neurohealth; Chris Long, DDDS; Dr. Bradley Meier, DPC; Ann Phillips, Parent; Mary Soligo, Christiana Counseling; and Dawn Stewart, Healthy Living

**GUEST**

William Strehle, Brain Injury Survivor

**CALL TO ORDER**

The meeting was called to order at 2:10 PM.

**APPROVAL OF MINUTES**

Devon noted that on Page 4, next to the last sentence, delete the word “help”. Motion was made, seconded and approved to accept the January 7, 2008 meeting minutes as amended.

**AGENDA ADDITIONS/DELETIONS**

- Lora added the TBI Grant Conference.
- Al Rose will provide an article on brain injury and soldiers in Iraq.

**BUSINESS**

**ABI Waiver Update—DSAAPD**

Lisa Bond and Guy Perrotti gave the following update. Lisa provided a hand-out on ABI Medicaid providers and Lisa will send Kyle an updated listing. CMS approved the ABI waiver in November with an effective date of December 1, 2007. A direct mailing was done to about 300 people on the elderly and disabled waiver listing. Fifty-six people have requested an assessment for the ABI waiver. Eventually after going back and forth with individuals on the waiver and family members, this number got down to about 38 people. As of today, there are 21 people that are open on the ABI waiver and there are five that are being worked on through the assessment process. There is one individual that is a new referral who is starting the Medicaid application process. Of the 21 that are open, 20 people reside in assisted living facilities, 18 at Peachtree in Sussex County and two at Garden Chapel in New Castle County. There is one person that is transitioning from the E&D waiver and the five other persons that are being assessed are in the E&D waiver. Families are taking a long time to assess the differences between the two waivers and make decisions. Some individuals have had multiple conversations with case managers and nurses before they make their decision. This is a good thing; however, it does take longer to roll people over in the waiver process. An enrollment packet and negotiations have been established with Easter Seals for an Adult Day Care in Sussex County and individuals should be enrolled into the system this week. Once Easter Seals is on board for Sussex County, all providers for services in all counties have been found. In the area of cognitive services, only two providers have been found so a re-recruitment for these providers is going to be conducted which will allow for better client choice.

Lisa added that at this time they have started paying some claims out under the ABI waiver. This is very significant to DSAAPD since this means that the systems are working. Another significant matter is, now that the system is up and running, you know where areas of more training are needed for the two contract case manager providers under the ABI waiver. On Thursday and Friday, DSAAPD's waiver coordinator and one of the nurse supervisor's are going to meet with the two case managers and do a walk through of all open 21 waiver clients to make sure all the needs of the clients are being met and that the clients are getting the correct services. Also, the overall quality assurance plan for the waiver is starting to take form and was to be worked on after six months.

Lisa added that a large massive outreach Medicaid campaign has been started. An article has been placed into the Better Years and the BIAD is putting the same article in their next newsletter so that people who are not currently enrolled in a waiver program are made aware of this option.

Lisa provided Jane with DSAAPD contact information for AI duPont's clients aged 18 and older who could apply for the waiver. Lisa offered to arrange for an in-service training for AI DuPont Hospital. Brian added that if folks feel that they qualify and they are "getting the run-around", they can contact Community Legal Aid for assistance. Or, they can insist on filing an application so, if they get denied, they can appeal. If individuals 18 years and older want to work, there is an income cap. Lisa will let Kyle know the income cap (percent of poverty level). Brian added that services for veterans with TBI are really being pushed nationally. Lisa will also let Kyle know if the veterans'

percentage will be changed due to them receiving a partial benefit for their disability. Brian added if so, is there a way to make that an exclusion.

Brian asked Guy if the money in the DMMA budget has been earmarked as part of the 5-8% percent budget cuts. Guy reported that, to his knowledge, the ABI waiver will not be cut.

Lisa and Guy added that DSAAPC will wait one year to get consumer feedback.

**Year 3 of TBI Implementation Grant (Funding, Registry, Waiver for Kids, TBI Action Plan Revision)--**

Lora gave the following update—

The year three grant has been submitted; however, DPH has not heard if we received the funding.

Lora shared TBI conference information and provided hand-outs. Conference information about children will be shared with Jane and information on veterans will be shared with Mike. A lot of the information from the CDC is available for free.

Lora added that the Director of the Traumatic Brain Injury Program in Maternal and Child Health talked about changes in the grant process next year (e.g. what the federal government will be looking for in the grant process. The next round of grants are expected to be competitive. Fewer grants will be awarded, but the amount is hoped to be as much as \$250,000 for about 20 states. There is also an increase in the match to 50% of the grant. The targets for the next round of grants will be children and youth, service members seeking help, and the elderly. Also, more partnerships are preferred. States are encouraged to have more partnerships and less reliance on specific organization. National performance measures will be established so that all states can be measured the same way and you can compare what is going-on state to state. However, Lora said that a consistent traumatic brain injury definition needs to be established for consistency throughout the states. Brian added that our current grant is for “traumatic” brain injury; however, the BIC deals with “acquired” brain injury which is a more inclusive definition.

Brian added the following information on the grant funding. The change/approach in the grant process is being prompted by some strategic consideration because President Bush has zero funding for the program in FY 09. Part of the rationale is that the Office of Management and Budget did their assessment and found that they could not document objectively the impact of the program in terms of client numbers, etc. What they are trying to do is to give more money to fewer states (20). That will allow the states that do not get any money to go to their Congressman and ask for money for the TBI program. Brian added that the bottom line is that is going to be difficult for DE to qualify for these grants so we are going to have to do a better job and submit a “top notch” application.

Laura Cygan spoke about her experience at the TBI conference. She reported that for all the states' contacts she spoke to have a strategic plan or action plan. This plan would outline where they are, where they want to be and how they are going to get there. All the states indicated that is really important to have all your key players from the state agencies represented. It was noted that the BIC does not have a representative from DOE at this time. A lot of other states have more governmental backing. Laura wants to examine DOE's definition of brain injury. Brian added that the BIC may want to take on this initiative through DOE or legislatively.

Another initiative that BIC may want to promote is that state regulated insurers cover cognitive re-training (Texas legislation) or school re-entry (Ohio's definition). Brian will bring more initiatives from the conference to the next BIC meeting.

## **PATBI Report**

### **I. DDDS ELIGIBILITY REGULATION**

The Division of Developmental Disabilities Services issued final eligibility regulations on March 1. The SCPD had commented on proposed versions of the regulations in July and October, 2007. In the October version of the proposed regulations, the Division had reinstated brain injury as an eligible condition but only if the applicant functions on a "mental retardation" level. The Council promoted a more liberal approach to brain injury eligibility but was rebuffed. Brian provided the DDDS commentary, final regulations, and Brian's March 10 critique. Brian's analysis of the brain injury standard was as follows:

Eighth, the Councils noted that DDDS had reinstated a limited eligibility authorization for persons with brain injury or neurological conditions similar to mental retardation in the October regulation. However, the Councils recommended adoption of less constrictive standards. DDDS declined to adopt any amendment. The Division's rationale is weak. It characterizes its core focus on persons with "significant cognitive and adaptive behavior deficits". At p. 1239. The anomaly in this characterization is that 3 of the 5 DDDS eligible conditions (Autism; Asperger's; Prader Willi) do not require a "significant cognitive deficit". Persons with such conditions could test as extremely bright and qualify for DDDS eligibility. Indeed, DDDS explicitly recites that no deficit in cognitive functioning whatsoever is required for applicants with such conditions: "The regulation clearly does not require an impairment in cognitive functioning in individuals appropriately diagnosed with Autistic Disorder or Asperger's Disorder." At p. 1241.

Although disappointing, the SCPD did prompt reinstatement of at least this limited eligibility for DDDS services. The July version had deleted all references to brain injury.

### **II. DHSS BUDGET TESTIMONY**

Brian presented testimony on behalf of the DLP, SCPD and DDC. at the February 27 and 28, 2008 JFC DHSS budget hearing. Brian provided copies of the presentations, minus attachments in his report. Also included is the DSAMH Director's presentation.

After consulting DSAAPD and the SCPD, Brian opted to not address funding for the ABI waiver. Brian confirmed that the funds were already included in the Governor's DMMA budget and it appeared imprudent to draw attention to this initiative given the current State budget shortfall.

#### A. DDDS Budget

The presentation on the DDDS budget focused on the latest attempt to initiate a "family support waiver", now renamed a "self-directed support waiver". The "content" and services menu of the new waiver proposal is almost identical to the one proposed for FY 08. Three month funding is sought. However, DDDS proposes to divert funds from residential services to the waiver rather than seeking a discrete allocation of funds for the new waiver. The Governor's proposed budget contemplates approval of a reallocation of funds to begin the waiver. Subsequently, the Governor requested agencies to identify budget cuts in FY 09. At the March 18 meeting of the DDDS Advisory Council, DDDS confirmed its intent to proceed with the waiver in FY 09 while identifying other contexts for cost-cutting.

#### B. DSAMH Budget

The presentation on the DSAMH budget focused on the need for community-based residential options (e.g. supervised apartments and group homes). DSAMH lacks sufficient capacity in community-based residential options.

### **III. S. B. 46 (MOTORCYCLE HELMET LEGISLATION UPDATE)**

In May 2007, the SCPD strongly endorsed this bill which would reinstate a requirement that adult motorcycle riders wear helmets. Stiff opposition to the bill was expected. See attached May 14, 2007 News Journal article, "Motorcycle Helmet Bill Faces Tough Opposition".

More recently, the News Journal published a March 27, 2008 article, "Helmet Option Suits Riders". The article describes a AAA Mid-Atlantic opinion poll in which 79% of Delawareans "believe a law requiring all motorcyclists to wear helmets would dramatically decrease the number of motorcycle injuries and fatalities." The article also notes that "(h)ead injuries are the leading cause of death in motorcycle crashes, and riders without helmets are 40 percent more likely to suffer a head injury and 37 percent more likely to die in a crash." The article also addresses medical costs: "According to the Delaware Office of Highway Safety, the estimated medical costs for injured motorcyclists in Delaware from 1998-2003 were more than \$16 million - of which 60 percent was attributed to motorcyclists who did not wear helmets."

A February 18, 2008 News Journal article, “Crashes Up, Death Toll Down on Del. Roads” recites that “(a)ggressive driving was also a factor in half of the 17 fatal motorcycle crashes last year, five more than the year before.”

The SCPD may wish to consider sending an updated endorsement of S.B. 46 which incorporates some of the information presented in the articles. It will be brought up at the Policy and Law to write an updated letter from the Council on this bill.

#### **IV. S.B. 174 (BICYCLE HELMET LEGISLATION)**

In 2005, the SCPD Brain Injury Committee sponsored DLP-authored legislation (S.B. No. 58) which raised the age for wearing a helmet while riding a bicycle, motorized scooter, or motorized skateboard from the 16<sup>th</sup> birthday to the 18<sup>th</sup> birthday and updated the helmet certification standards in the Delaware Code. That bill passed the Senate but not the House in the last General Assembly.

Similar legislation (H.B. No. 174) was introduced in September 2007. It passed the Senate after considerable debate on March 20, 2008. The Office of Highway Safety testified in favor of the bill. The legislation has been endorsed by the Office of Highway Safety, the Department of Safety and Homeland Security, and the Division of Public Health. Since this bill faces an uncertain future in the House, Brian is recommending that the SCPD solicit letters of endorsement from other organizations and agencies. This approach in 2005 resulted in endorsements from several organizations. Brian also recommends soliciting a letter of support from DMMA based on the following: 1) Office of Highway Safety’s medical cost estimate for injured motorcyclists without helmets (March 27 News Journal article); and 2) Maryland estimate of impact on Medicaid of injured motorcyclists without helmets referenced in SCPD’s letter of endorsement on S.B. 46

Parenthetically, consistent with a March 28, 2008 News Journal article, an 18 year old riding a bike with dark clothes and no helmet at night was recently killed in Kent County. Since he was 18, the bill would technically not have covered this rider. However, it provides an illustration of the need for this type of legislation to cover typical risk-taking behavior by teenagers.

BIAD; DLP; DDC agreed to sponsor the legislation.

#### **V. S.B. 227 (GOLD ALERT PROGRAM FOR MISSING PERSONS)**

This bill was introduced on March 20. It has been assigned to the Senate Finance Committee.

As background, Colorado adopted legislation in 2007 which expanded the familiar Amber Alert system to missing senior citizens and persons with developmental disabilities. S.B. 227 would establish a “gold alert program” for missing senior citizens, missing persons with disabilities, and missing suicidal persons. The alert would cover

both children and adults with disabilities or suicidal profiles. When State or local law enforcement agencies are notified that a covered person is missing, further information would be solicited from the person's family. The person's description would then be entered into both State and national databases. The media is also alerted.

The bill is generally well written. It would also be a valuable safety-net system for persons with TBI who are subject to memory loss and disorientation. Brian recommends that the SCPD and other organizations strongly endorse the bill. Brian did identify one grammatical error, i.e., the word "who" should be "which" in line 62. However, the error is minor and does not merit a comment.

Motion was made, seconded and approved to recommend that BIC strongly endorse the bill through the Policy and Law Committee.

## **VI. PILOT IEP FORM: SUMMER PROGRAMS**

By Delaware statute, special education students identified under certain classifications (TMH; SMH; autism; deaf/blind; orthopedic impairment; and TBI) **MUST** be offered extended school years/summer programs (Title 14 Del.C. §1703(e)(f). The SCPD and GACEC strongly objected to DOE adoption of regulations which essentially repudiated this entitlement.

The DOE has been "piloting" a new IEP form and is soliciting comments on the form. In the past, IEP forms contained an explicit "prompt" alerting teams that students with certain classifications were entitled to extended school years. The "prompt" is absent from more recent forms and the "pilot" form. The prompt is actually more important today since: 1) the DOE regulations omit any reference to this entitlement; 2) more eligible students are in mainstream settings as juxtaposed to special schools (e.g. Meadowood; Leach) which were familiar with the entitlement; and 3) IEP teams may be unfamiliar with the entitlement for low incidence classifications (e.g. TBI) and newly eligible students (e.g. students with Asperger's Syndrome are now classified under Autism).

Based on Brian's motion, the GACEC issued a March 14, 2008 letter on the pilot IEP. Brian recommended that the SCPD issue a more comprehensive set of comments supporting inclusion of a prompt in the ESY section of the IEP.

Brian is recommending that the SCPD send a letter to DOE (like GACEC's letter—just being more expansive on this issue) supporting that the pilot ID form includes a section identifying the students that are eligible by classification and some acknowledgement or documentation that the parents have been made aware. Motion was made, seconded and approved to write this letter.

Brian provided a bill he drafted regarding this issue. In part, it would add the following sentence: "Each public school shall ensure that a standard individual education program (IEP) forms prominently identify pupil classification qualifying for 12-month schedule

under the sub-section and document disclosure of such qualification to the parent, guardian or other person legally responsible for the pupil.” Brian noted that a DOE regulation says the school districts must use the DOE forms for secondary and primary education IEPs; however, districts can add this to their IEP forms. Motion was made, seconded and approved to support this initiative.

Brian suggested getting sponsors from the Senate and House Education Committees. Kyle and Wendy will solicit sponsors. Brian added that he would first like to get the bill introduced, then get letters of support and then approach DOE.

Kyle will send a copy of the statute to Jane.

## **VII. HRSA/CDC SENIOR CITIZEN BRAIN INJURY PREVENTION INITIATIVE**

HRSA recently distributed an informational package for seniors and their caregivers to facilitate prevention, recognition, and treatment of TBI. Materials can be ordered from the CDC website. Since DSAAPD is sponsoring the ABI waiver, the availability of these materials should be shared with DSAAPD.

## **VIII. NEW BRAIN INJURY PUBLICATIONS CATALOG**

In the past, the SCPD and BIA ordered materials from Lash and Associates which publishes a catalog of brain injury publications. The web address is [www.lapublishing.com](http://www.lapublishing.com). Some new publications are highlighted in the attached letter to the D.P.

## **IX. DOE/DSCY&F Grant to Integrate Schools & Mental Health System**

Although Brian was unable to attend that March 12 meeting of the DCMHS Advisory & Advocacy Council, he recently received the meeting materials which included a description of a project to facilitate identification and referral of students with mental health needs to community mental health resources, including the DCMHS. The project will operate until May, 2009. It would be helpful if students with TBI were included in the target population and referrals to the TBI support system were envisioned.

Brian recommended that the SCPD Brain Injury Committee solicit a presentation on the project to facilitate input and collaboration. The project might benefit from the many materials on TBI students compiled by the Committee and Brain Injury Association.

Kyle will e-mail Kathy Goldsmith and Susan Cycyk asking them or a representative to come to the BIC meeting to provide a presentation on the project.

## **TBI Materials**



Kyle provided hand-outs in today's packets of materials that were ordered with the \$3,500 grant monies.

## **BIAD Update**

Devon announced that the Governor's Luncheon was held in March. Governor Minner presented the BIAD with a proclamation declaring March as Brain Injury Awareness month. Dr. Jane Crowley was presented with the "Advocacy Award". The Brain Injury of America decided that the theme for National was going to be "Elderly and Falls". If you need any of this information, please let Devon or the BIAD know. Rusty Sheridan is a new staff member as well as a board member. A new director is close to being hired. The BIAD website is still in the works; however, Devon is working closely with the website consultant. The annual BIAD conference is Wed, October 22 at the Dover Sheraton. The theme of this year's conference is the "Military". If anyone has any recommendations on a speaker or materials, please let them know. The Spring Fling is Sunday, April 13 at the Modern Maturity Center in Dover at 4 pm. The cost is \$28 per guest; but \$14 for a survivor or family member. Everyone is welcome to attend. Please let the BIAD know ahead of time if you would like to attend or just show up and pay at the door! Advisory board members are needed.

## **Family Ambassadors Update & Other Issues**

Jane gave the following update. The ambassadors have made presentations to four or five emergency rooms in the state out of a total of eight emergency rooms. Seven presentations to schools have been made. St. Francis' Hospital has requested more brochures. In the medical arena, the idea is to get the emergency room staff to hand out a brochure on concussions.

The ambassadors hand out DVDs to the schools and brochures to the school nurses. A booklet is being developed which is an outreach to the school and which is aimed at classroom teachers on how to be aware of students' changes in behaviors if the grades drop. This brochure makes schools aware that if a student has a sudden behavioral change, it could be due to a possible concussion. Some symptoms are headaches, fatigue and difficulty in concentration. This information would make the teachers more aware and maybe allow the student a little more time to finish tests, etc. or the student may need some time off. Then the schools could make the parents aware that the student needs some medical attention.

A small brochure (tri-fold) is being developed to give to parents of children who participate in sports. Jane added that if you do not wait out a full concussion before returning to full sports activities, your child will be more at risk for a severe concussion. For some reason, and the experts are not sure why, there is a more catastrophic effect in adolescence concussions more than college-aged persons.

Jane added that resource information is being used from other states. Also, the concussion posters are given out to the schools to be posted for the athletes in the locker rooms.

Currently there are eight Ambassadors. Three medical who live in New Castle County, but cover the whole state and five educational—two in New Castle County and three in Kent and Sussex Counties.

Jane is concerned about no direction from DOE in reference to RTI (Response to Intervention) for students who return to school with mobility limitations and oriented to what is going on. There has been no reassurance from DOE that they will not be put in the wrong system. Kyle will ask Lori Duerr from DOE to come to a BIC meeting to make a presentation on RTI and how it impacts children with TBI—and what is their guidance to the districts as to how it applies to this population.

In summary, Kyle will also try again to get representatives from DOE and Child Mental Health on the BIC. Also, a representative from DE Youth Rehabilitative Services (YRS) would be a good addition. Wendy will let Kyle know a contact from YRS. Jane and Kyle had a contact at a conference with a person from a Philadelphia hospital that would be willing to talk, via conference call, about DEs TBI system. Jane noted that Pennsylvania has a great infrastructure in place for TBI so it would be a good idea to find out its procedures.

## **ANNOUNCEMENTS**

Al Rose passed out an interesting article on how soldiers' (returning from Iraq) concussion symptoms are tied to stress.

Mike Merrill announced that the VA opened a clinic in Georgetown and the Dover clinic will open the end of May. Social workers and psychologists will be in both clinics. At this time, the numbers are high for returning veterans' needing services.

The next meeting will be held on May 5 at 2 pm at the Appoquinimink State Service Center in Middletown.

## **ADJOURNMENT**

The meeting was adjourned at 4:20 pm.

Respectively submitted,

Kyle Hodges  
SCPD Administrator

S:bic/08apmin